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ANALYSIS OF DISEASE BEHAVIOR OF PATIENTS WITH HEMATOPOIETIC STEM CELL TRANSPLANTATION AND NURSING CARE

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Purpose To analysis the ill behavior of patients with hematopoietic stem cell transplantation. Methods The questionmaire of ill behavior was adopted and 17 patients with hematopoietic stem cell transplantation were asked to answer the questions. Results Faith in disease and belief in disease were both lower than normal standards. The index of double in disease fell in the normal, but their psychological orientation was higher. They were mentally healthy like a non-disease person but carried special psychologic behavior as patients with hematopoietic stem cell transplantation. Conclusions It is necessary to education patients with hematopoietic stem cell transplantation.

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STEM CELL TRANSPLANTATION FOR METACHROMATIC LEUKODYSTROPHY: A FAMILY CENTERED APPROACH

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At Sydney Children's Hospital, Stem cell transplant is offered as a potential cure to children who suffer from certain malignant and non-malignant diseases. When a family is confronted with the same life threatening illness in two siblings, the devastation and emotions are tremendous. As their 2-year-old daughter is diagnosed with Metachromatic leukodystrophy (MLD) the future of the unborn sibling remains unclear. As the family is told that curative treatment can only be offered to one sibling, they must simultaneously prepare for the inevitable death of the other.

This presentation will discuss the management of an infant undergoing a stem cell transplant at the age of 6 weeks, whilst his sister is receiving palliative care for the same disease. Metachromatic leukodystrophy is an autosomal recessive lysosomal storage disorder occurring in 1: 40 000 births. It is characterised by the accumulation of lipid (sulfatide) primarily in the central nervous system resulting in progressive neurodegenerative function. MLD is caused by the deficiency of the enzyme arylsulfatase which is responsible for the breakdown of sulfatide.

During the last decade, stem cell transplantation has been used successfully to correct several genetic metabolic disorders by replacing cells of haematopoietic origin that can restore the deficient enzymes in the recipient. The most common variety of MLD appears in early childhood, but the disease may also occur in adults. It usually leads to progressive paralysis and, in children, early death occurs.

The advances in diagnostic medicine made it possible to diagnose the newborn within weeks of life, offering the family some hope of cure. This presentation will discuss the approach the health care team took in looking after a transplant family who are on such a huge roller coaster ride, and it will describe how this family was managed on the transplant unit.

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TO BLEED OR NOT TO BLEED? THAT IS THE QUESTION (NURSING MANAGEMENT OF PATIENT WITH HEMORRHAGIC CYSTITIS POST BMT)

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Hemorrhagic cystitis is a syndrome of hematuria with symptoms of urinary tract irritability indicated by dysuria, frequency and urgency. Incidence varies according to conditioning regimen, preventative measures employed, and graft versus host disease prophylaxis used. There are two types of occurrences: 1. Early onset happens during or shortly after the conditioning regimen in which patients may have received cyclophosphamide, ifosphamide or busulfan. 2. Late onset occurs weeks to months after bone marrow transplant related to contraction of certain viruses.

BMT patient who are immunocompromised, viruses are reactivated and excreted in the urine. In general viral shredding occurs 2-8 weeks after BMT and resolves spontaneously within three weeks. Another risk factor that contributes to hemorrhagic cystitis is GVHD. The bladder epithelium is a target organ for GVHD to attack and immunosuppressed patients already having associated complications with GVHD have an increased risk for acquiring viral infections.

Standard treatment modalities of hemorrhagic cystitis are: 1. Hydrating patients with intravenous and oral fluids. 2. Continuous bladder irrigation. 3. Bladder Instillation with Alum, Carboprost, silver nitrate, phenol, prostaglandin, and hydrocortisone. 4. Giving smooth muscle relaxants for bladder spasms. 5. Antiviral therapy. 6. Cystoscopy. 7. Our center is studying NOVO-seven injections to help with the clotting mechanism.

The nurses have an essential role in early detection. Mnemonics that would assist nurses in patient assessment is "U PAAS BI." U-urinary output, P-pain management, A–assessment of urine, S–specimen collection for urine cytology, B–blood counts and I-infusion of blood products as necessary.

Chemotherapy and viruses may account for a substantial proportion of late onset and long lasting hemorrhagic cystitis in BMT patients. In conclusion, nursing plays a huge role in prevention, early detection and treatment of hemorrhagic cystitis.

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THE DEVELOPMENT OF A NEED ASSESSMENT TOOL FOR FAMILIES OF BMT PATIENTS

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BMT is now mostly used to treat patients with advanced malignancies. However, health care provider's attention is prioritized toward BMT patients for the BMT trajectory, although uncertainty of survival, high cost, many physical changes of patient cause significant distress, anxiety, and burden on family. Preliminary study findings suggested that needs of family of patient were consisted with the needs for information, assurance, convenience, proximity, and support. Therefore, this research was designed to develop the need assessment tool that can be used for identifying and assessing what are needs of family of BMT patients. The data for the tool were collected from in-depth interview with family of BMT patients, self-reports of health care provider, and literature review. From the content analysis, the needs were identified as 61 items. In order to test reliability and factor analysis, 120 family members of BMT patients were sampled from September 2001 to July 2003 in Korea.

Results from factor analysis, 9 factors were confirmed. Factor 1(Need for information of treatment procedure and patient's health status), Factor 2(Need for patient's comfort), Factor 3(Need for social support), Factor 4(Need for emotional support), Factor 5(Need for follow up care), Factor 6(Need for family's convenience), Factor 7(Need for self assurance), Factor 8(Need for reliable relationship with medical staffs), and Factor 9(Need for physical environment of BMT unit).

As results, the need assessment tool showed high reliability (Chronbach's alpha was .93) and exploring nine factors of needs for the family with BMT patient. The assessed need of family of BMT patients will guide health care providers for the family intervention program, and to serve the effective and evidence based care for the family with BMT patients.

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A SUPPORT NETWORK FOR PATIENTS AND FAMILIES AFTER BLOOD AND MARROW TRANSPLANTATION

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Patients who are treated with blood and marrow transplantation (BMT) may feel alone and isolated as they recover from this